

# **Medicaid Managed Long Term Services and Supports for People with Intellectual/Developmental Disabilities**

Washington State DD Council  
September 27, 2013

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**National Association of State Directors of  
Developmental Disabilities Services**  
**NASDDDS**

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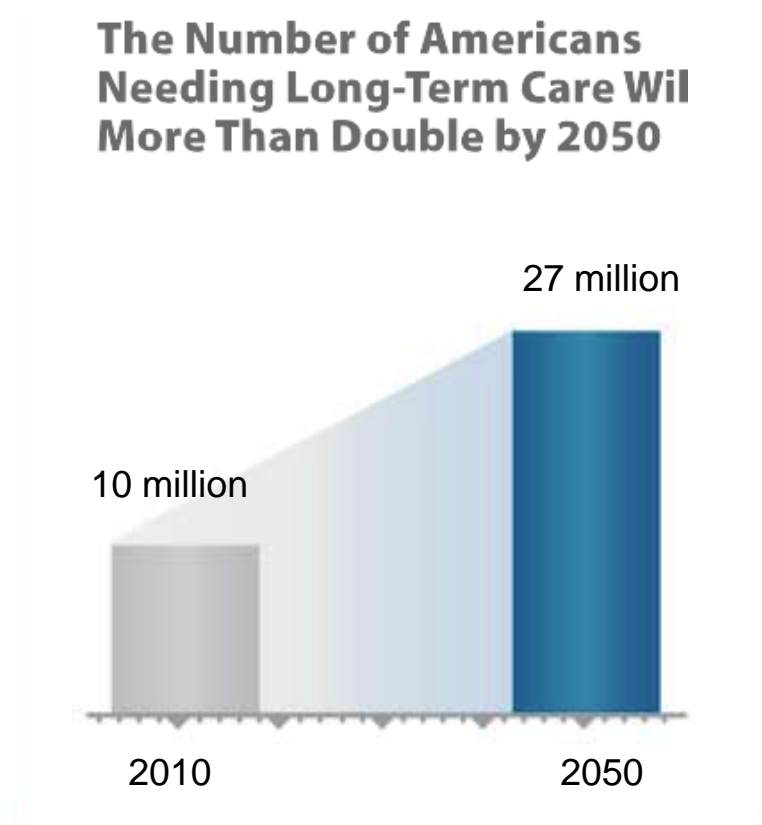
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## Confronting Our Realities

70% of Americans who reach age 65  
will need some form of long-term care for  
an average of three years.

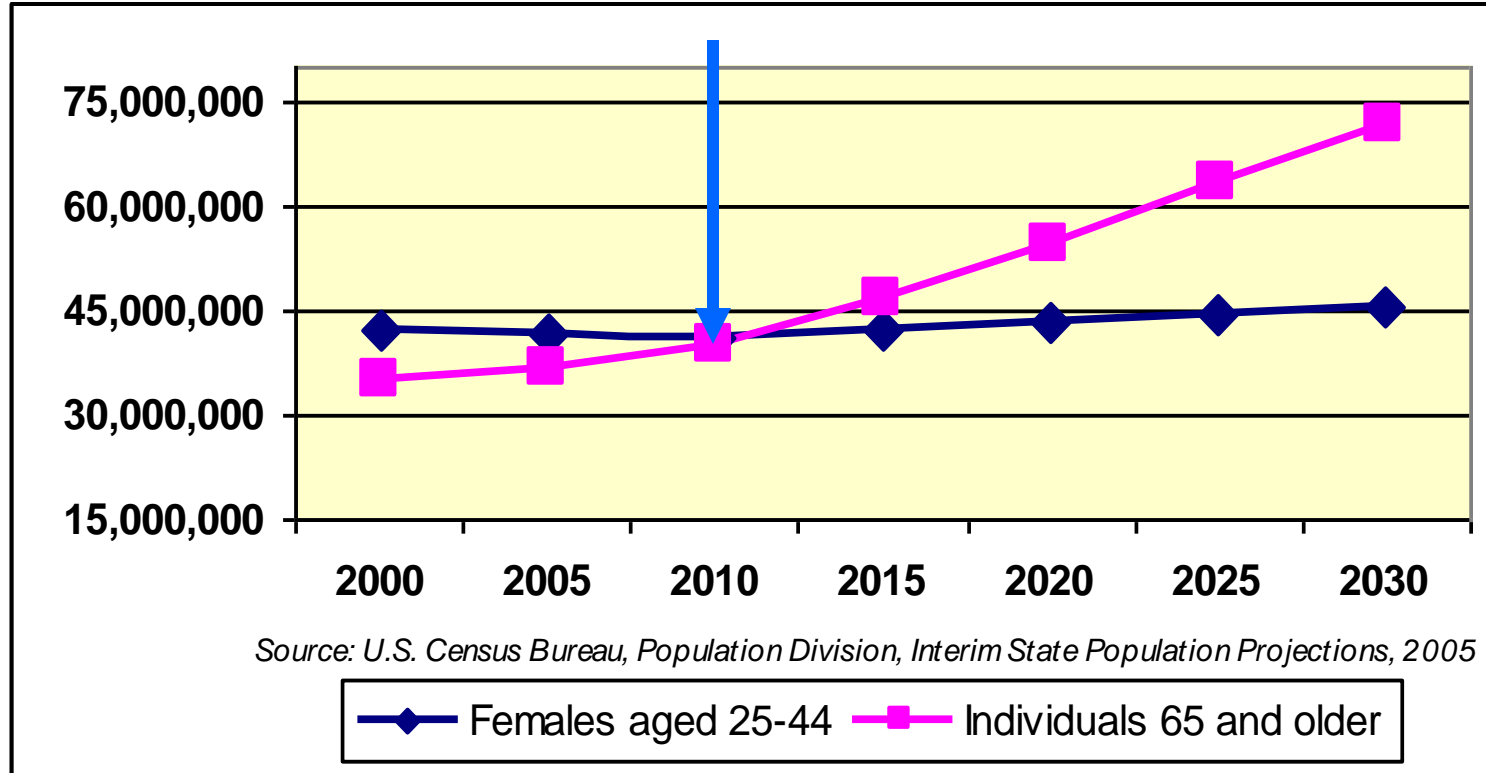


# Confronting the Realities



**JAMA** August 28, 2013 Volume 310, Number 8

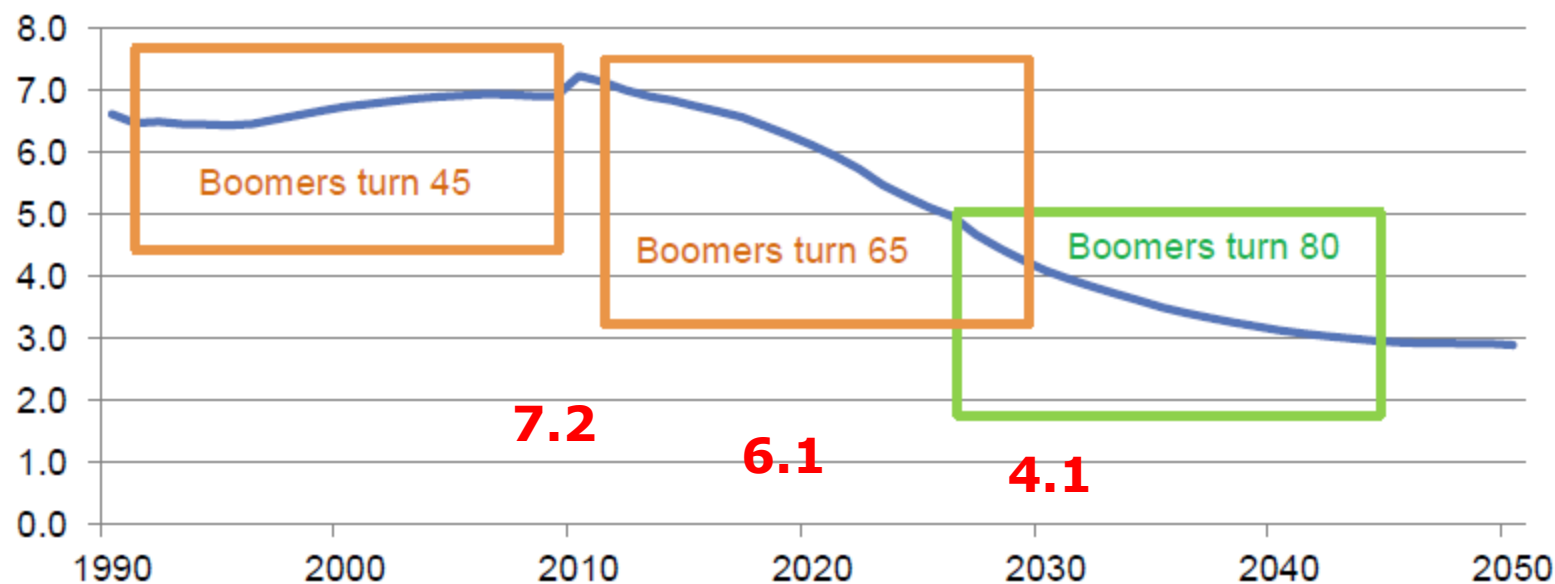
# Shortage of Care Givers



Larson, Edelstein, 2006

# The Care Giver Ratio Plummets

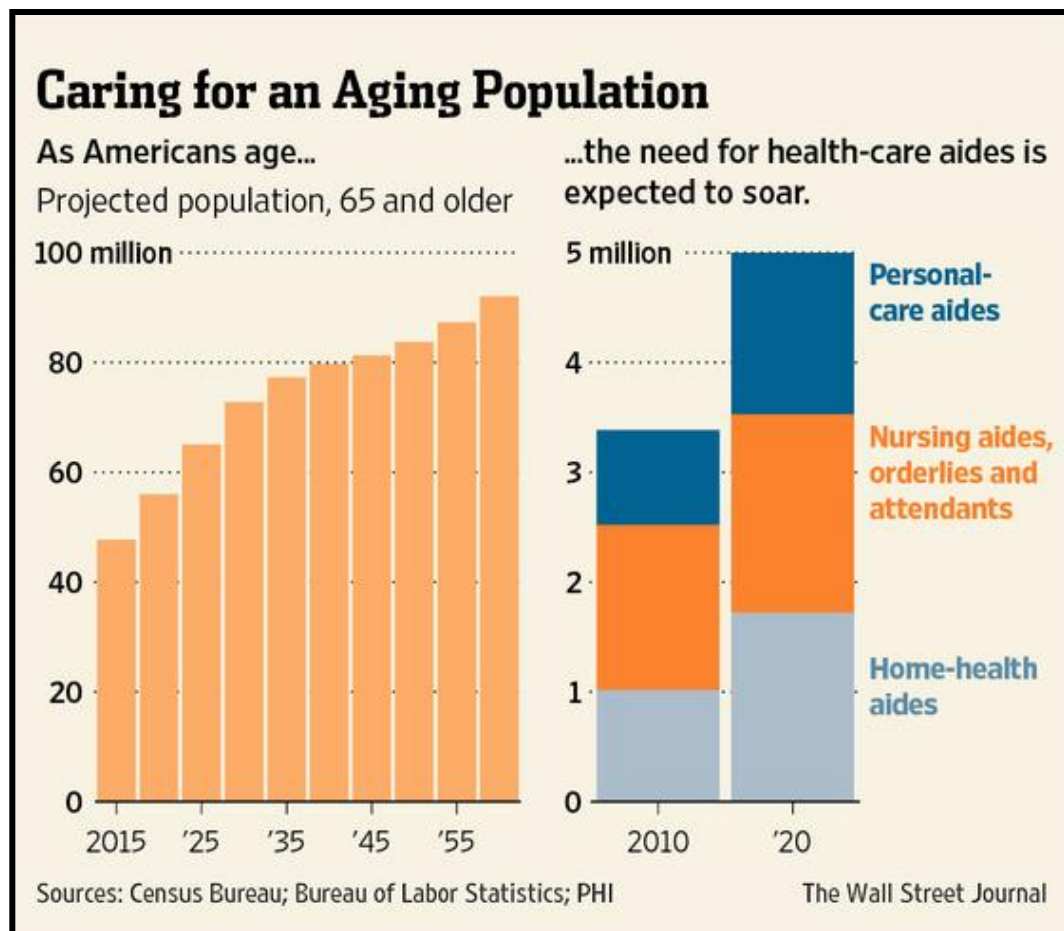
**Figure 1**  
**Caregiver Support Ratio, United States**



Source: AARP Public Policy Institute calculations based on REMI (Regional Economic Models, Inc.) 2013 baseline demographic projections.

Note: The caregiver support ratio is the ratio of the population aged 45–64 to the population aged 80-plus.

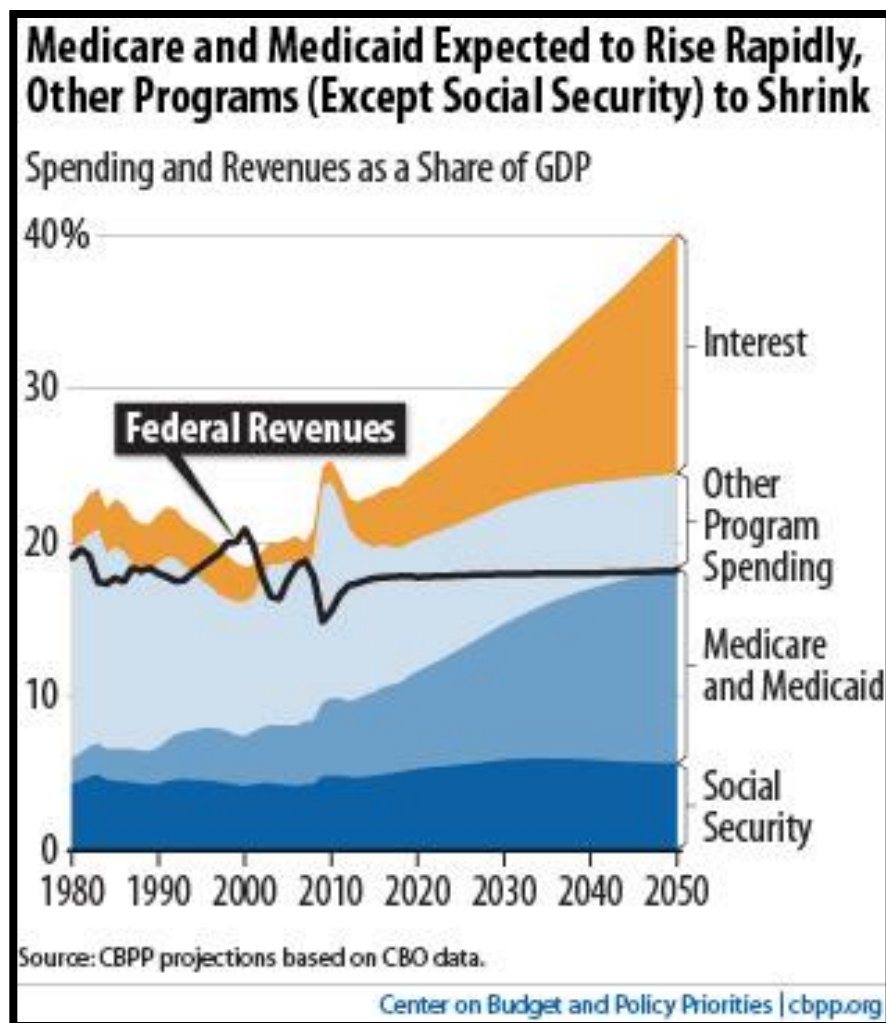
# Shortages of Care Givers as America Ages



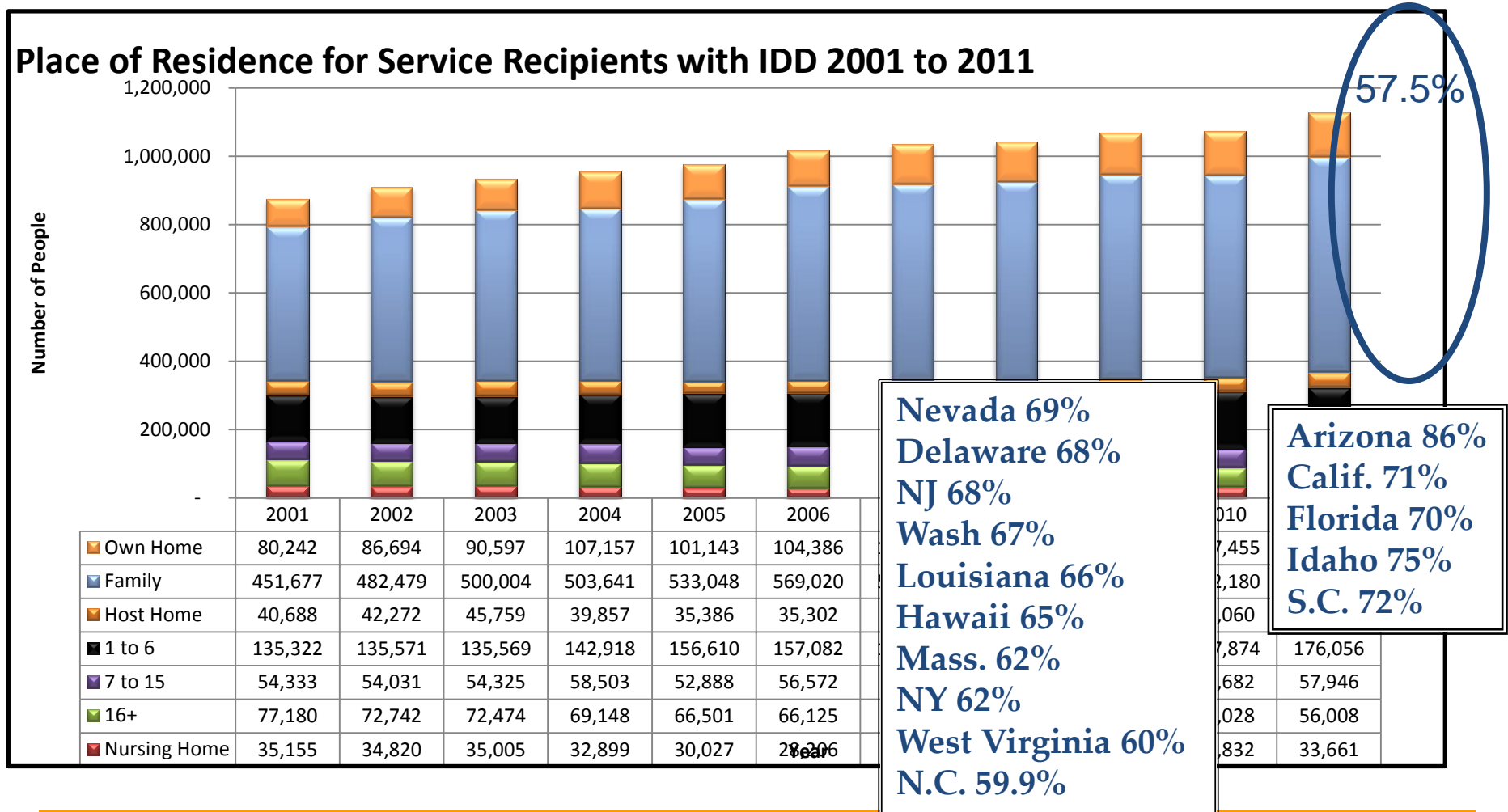
A labor shortage is worsening in one of the nation's fastest-growing occupations—taking care of the elderly and disabled—just as baby boomers head into old age.

Wall Street Journal  
April 15, 2013

# Medicare and Medicaid



# Medicaid LTSS Changing Context



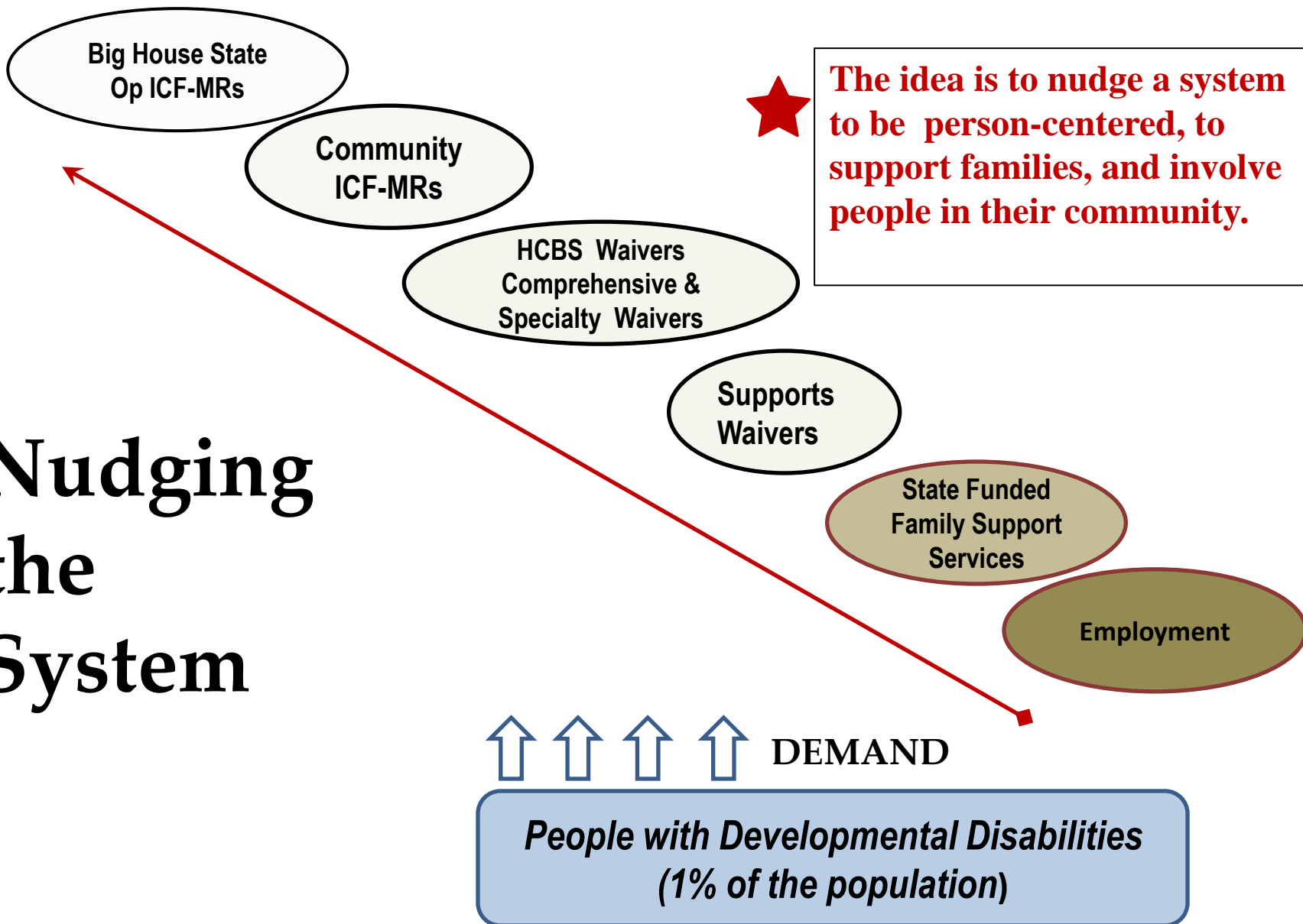


# So What are States Doing?



- **Focusing on employment**
- **Supporting families**
- **Rebalancing to community services and supports; less reliance on facility-based services**
- **Creating supports waivers**
- **Implementing resource allocation methodologies**
- **Looking at new federal authorities for HCBS**
- **Adopting managed care strategies**

# Nudging the System



# Why Managed Care



- Allows State officials to achieve budget stability over time and assist in predicting costs
- Can assist in limiting states' financial risk, passing part or all of it on to contractors by paying a single, fixed fee per enrollee
- Allows one (or more depending on design) entity to be held accountable for controlling service use *and* providing quality care
- Allows the potential to provide services to more people and create flexibility in service provision - - - - if done very carefully-----and all components in place

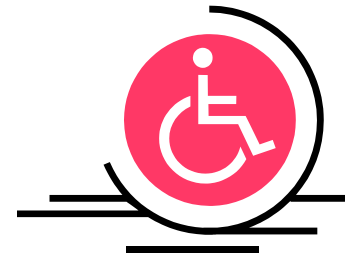
# Where is it?

## IN ACUTE HEALTH CARE

- 1 in 5 Americans are enrolled in managed care
- 65% of Medicaid participants are in managed care
- All states except Alaska, Wyoming and New Hampshire have managed care for Medicaid participants

## IN BEHAVIORAL HEALTH OR PEOPLE WHO ARE ELDERLY-LTSS

- Not everywhere but is much more common for seniors and for people with mental illness than it is for people with I/DD



# Managed LTSS Care in I/DD

## In Managed Care

- Arizona 1115
- Michigan b/c
- Wisconsin b/c
- Texas – to pilot I/DD 1115
- North Carolina- b/c going 1115
- New York – b/c
- Kansas - 1115
- California except people in HCBS Waiver 1115

## In Planning Stages

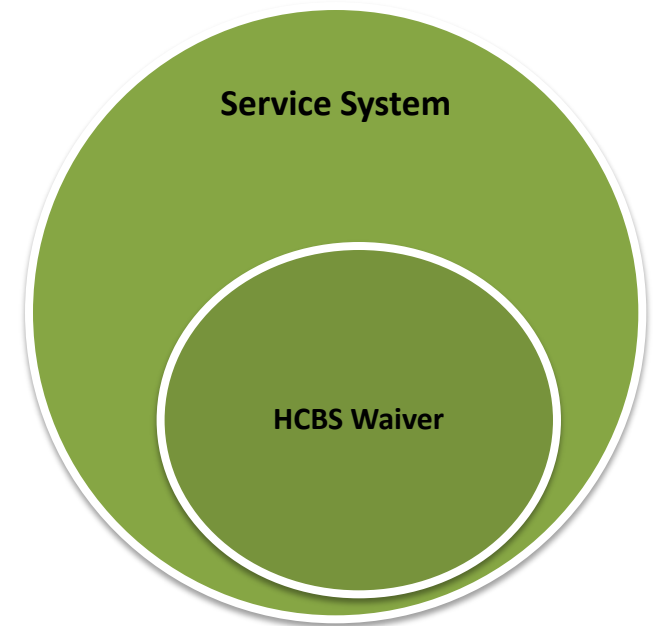
- Kentucky - discussion
- Georgia - discussion
- Louisiana - planning
- New Jersey - delayed
- Florida – legislative exploration
- Hawaii - discussion
- Illinois – in phase 3

# Managed Care – Why the Resistance?

What We all Know, but Many Others Don't

## Families Built DD Systems over 50 years

- 1950s & 60s - State programs and State Statues
- 1970s Right to Education
- 1980s Deinstitutionalization litigation
- 1990s Medicaid HCBS

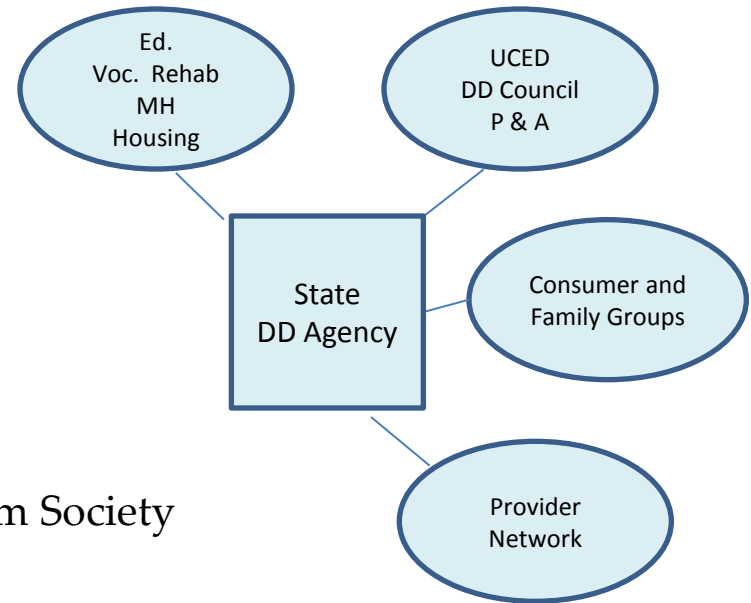


# Families Are Skeptical About Replacing the Current System

- **State DD Director** - high level executive branch
- **Families are valued stakeholders**
- **Single point of entry** – in a community based entity
- **Service coordinator** to assess needs, create a person-centered plan and monitor service delivery
- **Services** - Early Intervention for infants; Family Supports; Adult Services in and out of home including employment; emergency/crisis services
- **Provider network** almost exclusively non profits, started by families and faith based organizations; families sit on the boards and fund raise.
- **Oversight** through licensing, certification and monitoring of providers

# It is a System of Relationships

- **Interagency agreements with**
  - Education to transition students to adult life
  - Voc. Rehab
  - Mental Health
  - Housing
- **Partnership with and financial support of**
  - Parent Groups: Parent to Parent; ARC; Autism Society
  - Self-advocacy groups
  - Partners in Policy Making
- **Admin on I/DD (AIDD) Network –**
  - University Centers for Excellence in DD – training and research
  - Developmental Disability Councils- systems planning and service innovation
  - Protection and Advocacy – protection of rights





# Families and People with I/DD Are Skeptical About Hearing Managed Care will Control Costs

- No runaway budgets
  - Community services are not an entitlement
  - States manage within a limited appropriation
  - Enrollment is capped for each waiver
  - Individuals in many states have capped budgets
  - People with DD are not high users of hospitals or nursing homes
  - Thousands are on the waiting list
- The system has already rebalanced except in a few states
- **Saving money means cuts to services for people living with families – it always has in the past**

# What's Important to Families and People with I/DD

- Access to Service – Eliminating Waiting Lists
- Transitioning from school to adult life – a real job with needed supports
- Support for families that is flexible, meets their needs and is consumer/family directed
- Their sons and daughters having a good and happy life with friends, family, a valued role in the community
- What happens to their sons and daughters when they die? Who will be there for them?

## **For the person with I/DD**

- Can I work, have a good place to live, be in the community, have friends??

# What Families Need to Hear and Have in Managed Care (or in any system)

- Vision and Values – there is a purpose beyond “coordinating care and reducing costs”
- The words
  - Support families
  - School to work transition
  - Competitive employment
  - Self-direction – control over services & budget
  - Small, innovative providers (*run by families*) in their community will continue
- Eliminate waiting lists
- Collaboration with consumer and family groups & associations....they will have a say the way they do now

# IDD and Seniors & Disabled are not the Same

- **Focus**
  - Seniors- Supporting people well in their last years of life
  - IDD - “Getting a Life”
- **Length of Service**
  - Seniors - 2 to 3 years (on average)
  - IDD - up to 60 years
- **Cost Savings**
  - Seniors - State is liable for nursing home reimbursement which is provided on demand.
  - IDD - State financial liability is controlled because 1) there is no demand for ICFs/MRs; 2) HCBS has caps on enrollment; types, frequency and duration of services; and individual budget caps; 3) waiver cost effectiveness formula applies
- **MCO Financial Incentives**
  - Seniors – to provide HCBS to avoid NH costs
  - IDD – no incentive to provide anything, particularly family support or employment: families will not ask for ICFs

# IDD and Seniors & Disabled are not the Same- Managed Care must differ

- **Care and Supports**
  - Seniors - medical needs primary/LTC services related to medical management issues and attendant care
  - IDD - involvement in the community primary; services having little to do with health condition
- **Primary Services**
  - Seniors - medical and personal assistance
  - IDD - habilitation, training, employment, family supports
- **Family Care Giving**
  - Seniors –Involvement increases near the end of life
  - IDD -Begins at birth and is there through a life time
- **Natural Supports**
  - Aged - have a life time of natural supports to rely on
  - IDD - need to build and maintain them throughout life

# CMS Expectations of Managed Care Programs

1. Adequate Planning and Transition Strategies
2. Stakeholder Engagement
3. Enhanced provision of HCBS (ADA/Olmstead)
4. Alignment of Payment Structures with MLTSS Programmatic Goals
5. Support for Beneficiaries
6. Person-centered Processes
7. Comprehensive and Integrated Service Package
8. Qualified Providers
9. Participant Protections
10. Quality



# National Council on Disabilities Principles

- **The principles address:**
  - Personal experience and outcomes (1-4),
  - Designing and managing a managed care system (5-14),
  - Managed care operating components (15-16), and
  - Participants' rights (17-20).
- Recommendations to CMS:  
[www.nasddds.org/pdf/CMSMANAGEDCARENCDRRECOMMENDATIONS 1.pdf](http://www.nasddds.org/pdf/CMSMANAGEDCARENCDRRECOMMENDATIONS1.pdf).
- Guiding Principles:  
[www.nasddds.org/pdf/MANAGEDCARENCDRPRINCIPLES 1.pdf](http://www.nasddds.org/pdf/MANAGEDCARENCDRPRINCIPLES1.pdf)



# The principles outline what should be included in MCO contracts



- Person-centered practices
- Consumer choice among qualified providers
- Support for family caregivers
- Service plan monitoring to assure good supports & are delivered as planned
- The option to self-direct services, hire & fire staff, ind. budget
- Grievance and appeal processes
- Provider monitoring
- Policies to reduce & eliminate restraints, abuse, neglect, reporting and investigating incidents



# *Readiness and Phase-In: Readiness Assessment*

- Can't be overestimated!
- Like Facebook says-"It is complicated"
- Heavy stakeholder involvement
- Implementation, ensure safety, health & welfare
- Keep what is working-don't lose the decades of good values based, non medical community focus – it is hard to do everything– checklists, planning, stakeholder review, etc.
- Outcomes
- Safeguards
- And more!



# Readiness Assessment Includes an Thorough Examination of.....

- Stakeholder involvement in system planning, monitoring and assessment
- The provision of services to all who qualify without waiting lists
- The inclusion of all Medicaid state plan services in the service package to ensure movement from high cost institutions to community alternatives
- The experience and qualifications of staff responsible for managing the managed care system
- Provider networks
- Information and outreach
- Back up planning
- Payment structures, automation and paying the bills
- Transition planning, transition planning, transition planning

## 2. Stakeholder Engagement

- At the beginning, families and people with I/DD need to hear how managed care will be adapted to
  - Deliver support services (not just acute services)
  - Deliver on-going sustained services and adapt changes in the person's life
- During development
  - What we are looking to keep
  - What we are collectively looking to improve
- On going – How is it working: feedback, listening session, ongoing engagement



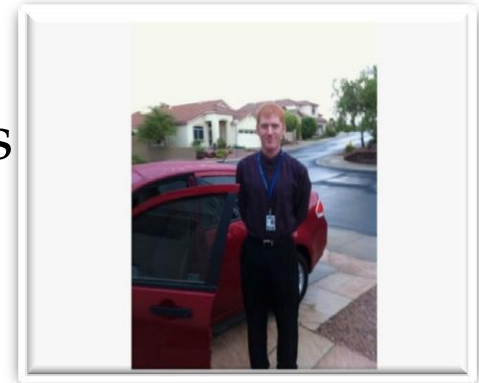
## 2. Stakeholder Engagement – cont.

- Transparency means
  - Sharing metrics/outcomes along the way. (EQRs can be hard to decipher)
  - Working together to identify population specific and MCO specific data to review & opportunities for improvement
- A seat at the table in policy development, not just review, for home and community based services enhancements
- Statewide groups are good; local groups with state involvement keep people involved and participating
- Fully Engage Existing ID/DD (& Mental Health)  
Expertise – Acknowledge Expertise Will Be Different



### 3. Most Integrated

Things most know but need to be outlined in MCO contracts



- Everybody can live in the com. In family homes with support
  - In their own homes
  - In shared living
  - Children and adults
  - Employment
  - Irrespective of medical or behavioral labels
    - People with trachs, g-tubes, suctioning, ventilators, medical frailty
    - People with behavioral reputations; criminal offenders
- Reduce use of nursing homes, ICFs, larger settings

## 4. Aligning Payment Structures with Goals

- Capitation includes the ICFs, nursing homes (all congregate settings)
- Invest savings in waiting list and desired HCBS options (supporting families, employment, smaller settings)
- Capitation does not look solely at historical data, utilization, and regulatory changes: It looks at:
  - Desired policy changes, focuses on future, valued outcomes—more in home supports, crisis support to prevent out of home placement, employment, early intervention

## 4. Aligning Payment Structures with Goals cont.

- Rate setting- what components will be retained by the state vs. what the MCOs will have authority over?
- Network oversight to ensure that the rate structure supports desired outcomes – increase in home support, support families, employment
- Enforcement – consequences for not achieving outcomes
- Rate modeling to increase specific, desired services

# 5. Supporting Beneficiaries

## Support Coordination in Managed Care-

### How do we get there from here?

- More than the coordination of benefits, goods and services
- A person who:
  - Does not work for a provider (conflict free)
  - Develops a relationship with the person and family
  - Develops the individual plan with them
  - Conducts on-going oversight (checks in) to make sure services are delivered and are achieving outcomes
  - Is available for ad hoc problem solving

If the State is not the MCO- how will the State make this happen?

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## 6. Person-Centered Practices

- It is a process for both planning and service delivery, not an instrument or tool. MCOs in more traditional managed care may look at the assessment or tool as the planning process
- Person centered means conducting all activities from the person's point of view – what is important to them
- Balancing what others believe is important for the person against their right to self-determination



*Home is where you hang your heart.*

*What do you do for a living?*

## **Medical Necessity? Social Supports? Having a Good Life in the Community**

Community Living in  
Managed Care- Social  
Support & Services to Have  
a Good Life in the  
Community

Balancing and Defining  
What Makes Sense to make  
a plan that is “necessary”

# Assessment & Options Counseling VS. Conversation and Person-centered planning

Assessment & Options Counseling	Conversation & Person-Centered Planning
<ul style="list-style-type: none"> <li>• Need is absolute: if X, then Y</li> <li>• Assessment leads to knowing what is needed</li> <li>• Based on presenting a list of services – leads to service assignment</li> </ul>	<ul style="list-style-type: none"> <li>• Need is situational &amp; personal</li> <li>• The person defines what is needed</li> <li>• Based on removing barriers- leads to natural supports, community resources as well as services</li> </ul>

## 6. Person-Centered Practices

Example- Opportunity in Managed Care- but not how MCOs not working in I/DD may think

- The person wants to be a fireman.
  - Determine why. Status? Uniform? Excitement? Honor family history? Image of strength? They like the fire house?
- The person-centered plan developed explores:
  - Opportunities to visit the fire house
  - Opportunities to volunteer
  - Opportunities that include wearing a uniform
  - Joining a gym to increase physical strength

## 6. Person-Centered Practices

### Example- Opportunity in Managed Care

- The person needs to reduce weight (Types II Diabetes) but is not motivated.
    - Create opportunities for enjoyable physical exercise (get a dog to walk; start a dog walking business; volunteer with the park service (uniform and name badge and exercise)
    - Offer cooking classes that are appealing to the person
    - Education about diet
    - Counseling by nutritionist
    - Join Weight Watchers
    - ETC.
-

## 7. Comprehensive and Integrated Service Pkg. Example

Individual is self-abusing by hitting their head; is aggressive toward others; does not have speech.

Integrated Assessment:

- **Medical** conditions that cause pain: sinus; migraine; broken bones; abdominal condition; medication side effects; dental pain;
- **Behavioral Health:** sleep and mood charting; functional assessment; PTSD assessment;
- Abuse and/or neglect; loneliness; boredom, other environmental factors

From the assessment, create an integrated intervention and positive plan

## 7. Comprehensive and Integrated Service Pkg.

### Transitioning Support between Services and Settings

- Focus on what assists people to stay in their home and community
- Having an active life and meaningful day for prevention
- Begin discharge planning immediately when a person enters the hospital
- Identify what prevents psychiatric hospitalization:
  - Crisis avoidance; positive behavioral supports; medication management; employment

# Acute and Long Term Care Coordination



Coordination discharge planning, avoiding illness, prevention, supporting wellness, framed around the values of community living. Support Coordinators/case managers need a unique set of skills/understanding



# Employment

Employment is a critical pathway to inclusion, independence and community living

Plans must increase access to employment- is it in the network plan? (Remember network plans in LTSS don't stop with drs. & clinicians, expand & hyper focus on ROBUST network adequacy for supported employment (and small housing, respite, family support, in home support services, etc.)

Clinical guidelines should be person centered, easy to use, and highlight employment

# Supporting Family Caregivers

- Families should receive the assistance they need to effectively support and advocate on behalf of people with disabilities
- Managed care can expand in-home supports, assist in addressing the waiting list and families can be paid to provide care

*Sustainability depends on how well we support families and get people jobs.*



## 8. Qualified Providers

- Basics are certification, licensing, background checks, credentialing (for clinical services), credentialing agencies
- Basics are not enough – providers need training in I/DD, supporting families and the value base of the services
- Keeping small providers and the rich network of HCBS agencies known in the I/DD community
- Provider agencies not traditionally in managed care may need training in billing, encounters, coding & other insurance based knowledge. Hold learning sessions, hotlines, T.A. and manuals
- Assure the training of non-certified direct support professionals; establish a core curriculum
- MCO staff and enrolled providers need training on person centered processes, I/DD, self direction
- Involve people with disabilities and families as trainers

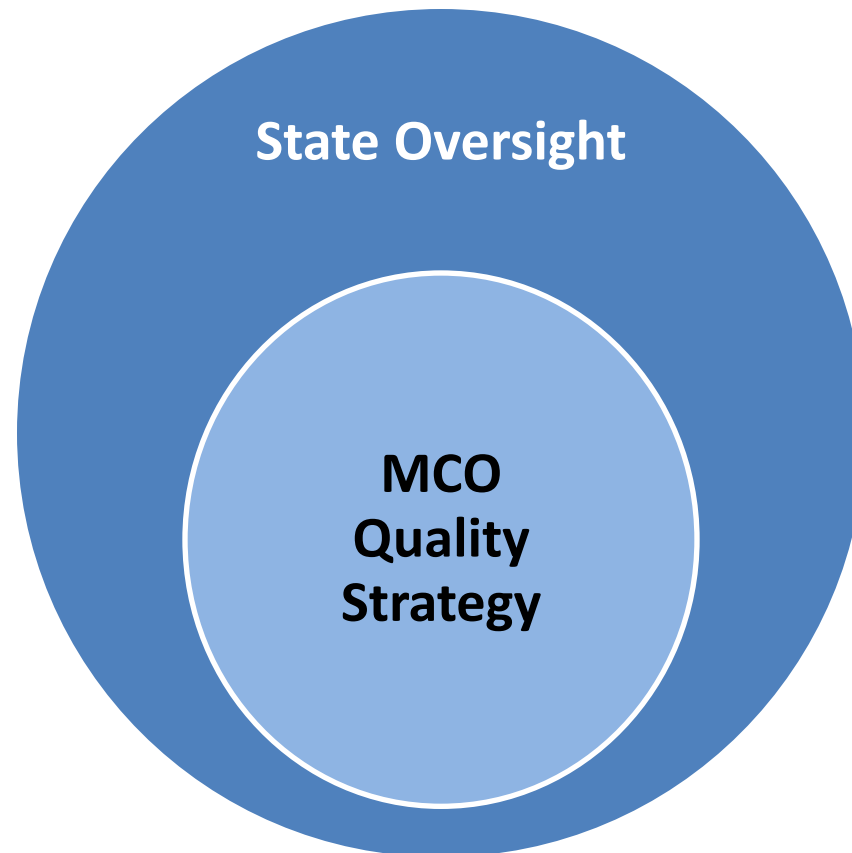
## 9. Participant Protections Rights and Responsibilities

- MCO responsibilities focus on dignity, respect, privacy, informed consent, due process, non discrimination, choice of network providers
- “Member responsibilities” focus on providing accurate information, follow plans and instructions, participate in mutually agreed upon plans and decision making

## 9. Participant Protections Rights and Responsibilities

- There are more rights and protections to include:
  - Right to most integrated settings
  - Fair compensation for labor
  - Right to own property
  - Right to date
  - Freedom from abuse and neglect
  - Right to presumptive competency
  - Right to be free from excessive medications
  - Right to contact Human Rights Committees
  - Rights specific to residential services

# 10. Quality



# OUTLINE OF THE STATE'S ROLE

- ❖ State staff with expertise in I/DD as well as managed care
- ❖ Ensuring that people with disabilities and families have access to information about the plans and a problem resolution process
- ❖ Designing and executing a contract with MCOs to achieve outcomes
- ❖ Ensuring that statutes, rules, policies-everything that stakeholders developed over the decades are followed?
- ❖ Conducting oversight and imposing corrective actions
- ❖ Public reporting on the performance of MCOs
- ❖ Staying engaged with stakeholders

# Outline OF the State's Role, Cont.

- **Managing & overseeing the system**
  - Establishing contract requirements and performance standards
  - Requiring Performance Improvement Projects including mandatory projects such as employment, supporting families.
  - Developing policies, manuals, clinical practice guidelines
  - Measuring access to services, ADA compliance, health and safety, increase in community living, decrease in large residential services and institutions
  - Review CMO quality management systems
  - Monitoring feedback from program participants through complaint systems, hotlines, consumer surveys & outreach sessions with stakeholders
  - Operational and financial reviews
- *Enhanced expectations increase innovation and build capacity in lifespan supports.*



# A Sample of Things to Look For in the Contract

- A requirement to do a person centered plan for LTSS- including the person, their family and others important to the person- check out the values and mission in other states' contracts
- Basis for service approval/denials
- The inclusion of services that are valued e.g.
  - Employment
  - Family support
- Requirements for school to work transition
- Fiscal incentives balanced with consumer protections

# Quality

- Comprehensive
  - Incident management
    - Reporting; monitoring; trending individuals, providers and MCOs
  - Evaluate Support Coordination
  - Participant Feedback
  - Utilization – who is receiving supports and where, underserved, targeted areas?
  - Review and trend grievances, complaints, appeals, claims, provider monitoring, incidents, quality of care concerns, outcomes, PIPS, and compliance data
- *The oversight of the MCOs quality by the State is as important as the MCOs system*

# Quality Oversight of Network Development and Capacity

- Provider network for HCBS services, in home supports, employment for people with the most significant disabilities, positive behavior supports, clinical experiences with I/DD, meets the specific needs of communities, geography, types of people services
- Approved and monitored by the state agency quarterly
- Gaps and improvements considered for future outcomes and PIPS

# Beyond the MCO Contract

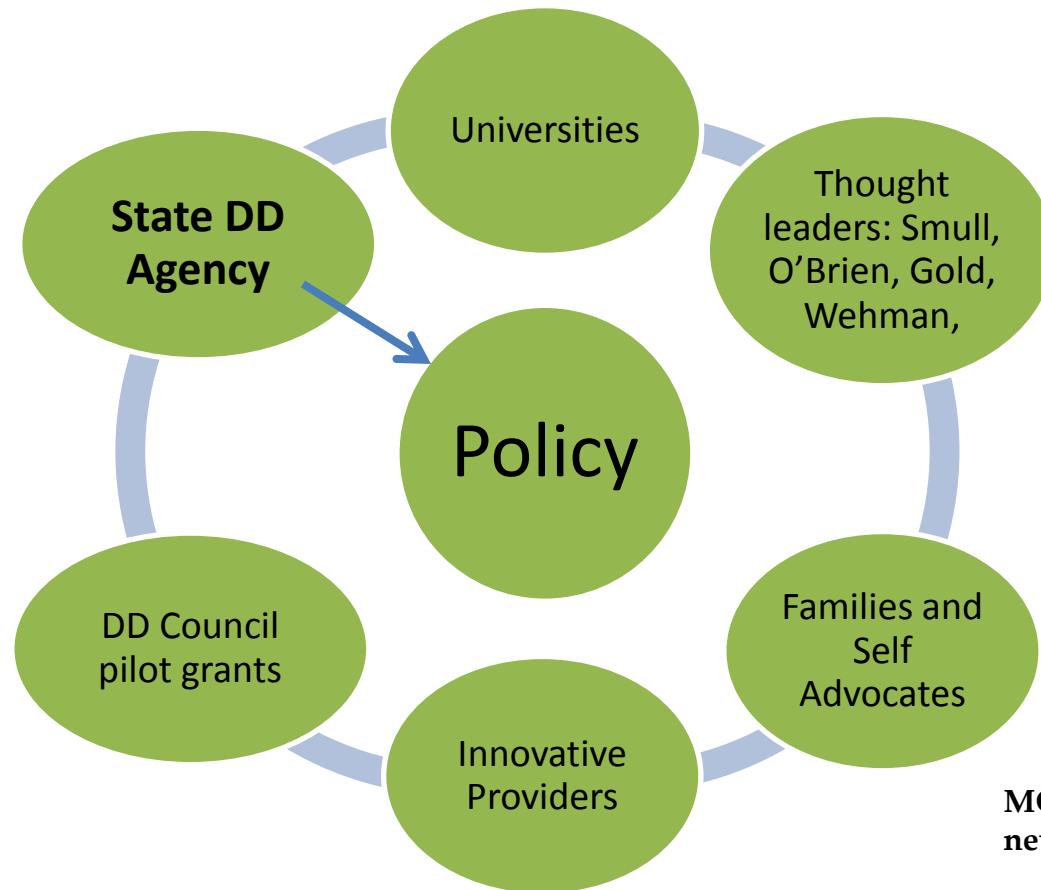


- State staff expertise in I/DD
- Performance Improvement Projects including non mandatory clinical projects: such as employment, supporting families, in home supports
- Network plans
- Outcomes data: increase in community living, decrease in large residential services and institutions reported quarterly
- Policies, manuals, clinical practice guidelines from State Agency outlining expectations, and State oversight. If functions are delegated, need state review and approval process for above
- Operational & financial reviews
- These enhance expectations, increase innovation, and build capacity in lifespan supports

# Innovation

## Wherefore Art Thou?

# Innovation In Managed Care - a Concern Without Intentional Focus on Moving Forward



## Innovations

- Individual Services Plans
- Positive Behavioral Practices
- Supported Employment
- Person-Centered Practices
- Self-determination
- Applied Behavioral Analysis

**MCO provider lockouts could discourage new innovative providers**

**No private market therefore no private sector innovation**

# Continuous Innovation

- Building a resilient community infrastructure
- Beware of “locking in” to set models
- Service designs & support strategies that enable people to get what they need not just what is available
- Policy must stimulate and support innovation
- Improving access
- Forging creative and productive partnerships
- Promoting the use of natural and community resources
- Remember how much innovation has come from people with disabilities, families and leadership already! Positive behavior support, supporting families, employment first, shared living – keep it going!

# **The Question Is.....**

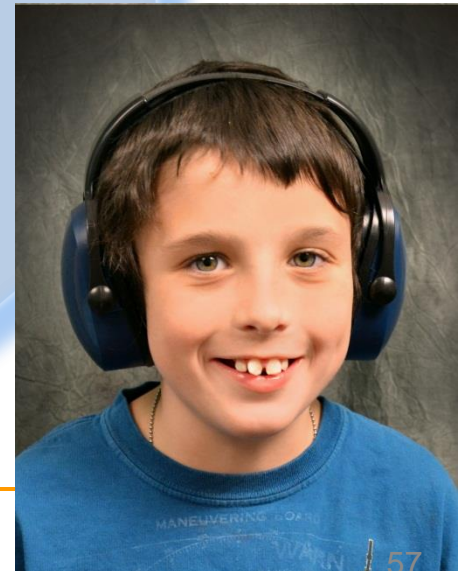
**Not whether people who need long term supports and services will be living with and relying on their families for support but.....**

**whether people and their families will struggle alone or have a great life because the supports are there for them and they are part of their community.**



# Measuring Progress

**Managed care is more than a financing mechanism.  
Defining quality outcomes for people with disabilities, seeking opportunities for integrating care, self direction, and supporting more people and their families in the community=  
Progress.**



**Thank You!**  
**National Association of State Directors of Developmental Disabilities  
Services**  
**[www.nasddds.org](http://www.nasddds.org)**  
**[bbrent@nasddds.org](mailto:bbrent@nasddds.org)**

